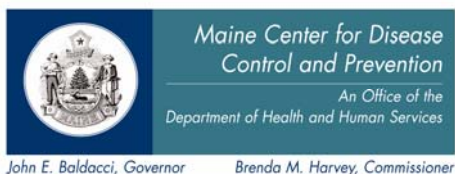


Genetics and Newborn Screening

Maine Center for Disease Control and Prevention

Maine Department of Health & Human Services

- ❑ Over 100,000 people in Maine are at risk for adverse health effects of inherited disorders or birth defects.
- ❑ Every year, 400-750 infants born in Maine may have a birth defect identified before age one.
- ❑ 70% of all pregnant women in Maine choose to have a screening test for Neural Tube Defects i.e., Spina Bifida and also Downs Syndrome, allowing for early intervention and treatment.
- ❑ The Genetics and Newborn Screening Program identifies approximately 5 infants each year with metabolic disorders. Treatment for these conditions can prevent mental retardation and other health problems, including death.



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The overall goal of the Genetics and Newborn Screening Program is to assure that Maine individuals and families will have access to comprehensive genetic services that will enable them to reach informed choices and to increase their ability to live healthy and productive lives.

Program Goals:

- ❑ To provide comprehensive genetic services to Maine families who are at increased risk for genetic conditions.
- ❑ To reduce mortality and morbidity from birth defects and other genetic conditions.
- ❑ To screen all infants born in Maine for conditions which, if left untreated, would cause mental retardation, health problems or death.

Priority Populations:

Individuals and families in Maine who have or are at increased risk of having a birth defect or genetic condition.

Program Activities:

- ❑ Evaluate and interpret incidence data for genetic conditions, including birth defects and congenital hearing impairment and their impact on public health.
- ❑ Screen all newborn infants for conditions (such as PKU (phenylketonuria) causing mental retardation, health problems or death, according to Maine State Law. The only exception is parent refusal for religious reasons.
- ❑ Provide quality assurance, tracking and case management for the Newborn Screening Program and the Newborn Hearing Program. Develop a long-term follow-up system to monitor outcomes of screening and treatment.
- ❑ Coordinate services and referrals to agencies and other programs.
- ❑ Provide technical assistance to the thirty-two birth hospitals in Maine regarding newborn screening and newborn hearing screening.
- ❑ Provide education and training to professionals regarding genetics, birth defects, newborn screening and newborn hearing screening.
- ❑ Administer grants to three genetic service agencies to provide comprehensive services related to genetic conditions. These services include:
 - * risk assessment * laboratory/clinical diagnosis * counseling,
 - * case management/referral * education of providers, clients, and the public

Funding Sources:

Funding is provided through Title V Maternal and Child Health Block Grant, Centers for Disease Control and Prevention, state General Funds and newborn screening fees.

Budget: \$1,181,799 (FY 2005) - 50% General Fund, 38% Federal, 12% Dedicated Revenue

Staff Count: 5